

INDEPENDENTLY

NEWSLETTER

June 2008

Charging into poverty?

Charges for care services at home and the national debate on adult care reform in England



June 2008

Coalition on Charging report highlights

The impact of charging on older and disabled people

The newsletter from NCIL for disabled people about Independent Living, Direct Payments, Individual Budgets, Personal Assistance & more...

Also available in large print, Braille, audio tape, PC floppy disc, email and on Website



National Centre for Independent Living

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Charity no.1113427

INDEPENDENTLY CONTENTS

04	Charging into Poverty - Coalition on Charging report
06	OUR LIVES OUR CHOICES – Independent living Bill campaign
08	UK considering reservations to UN Convention on the Rights of Persons with disabilities
11	Individual Budgets
13	News in brief
14	User led organisations development fund
17	Research project for the Equality and Human Rights Commission
19	Sad News
21	High Court rules that anti-discrimination law does apply
22	NCIL room hire



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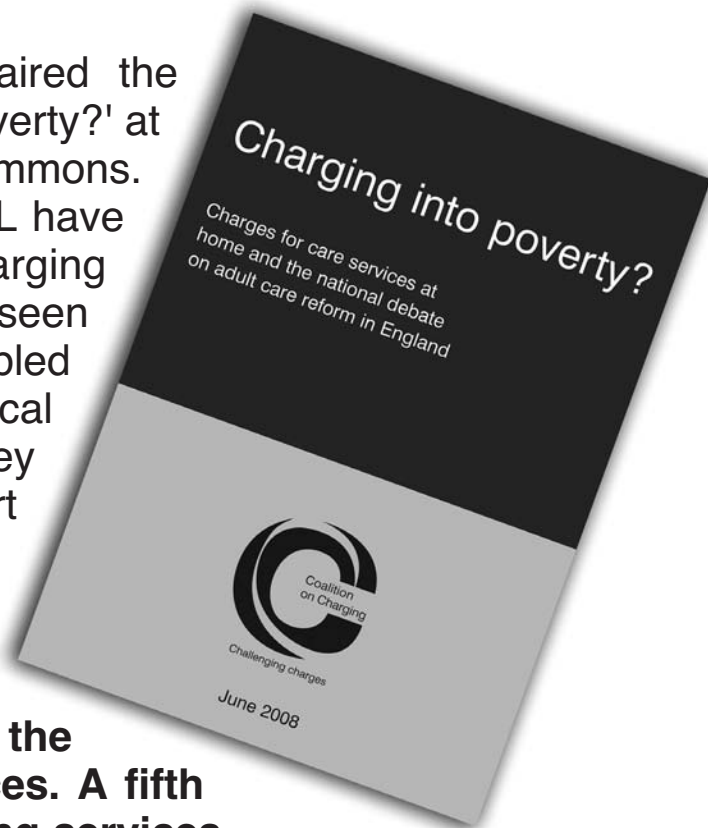
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We reserve the right to edit articles.

CHARGING INTO POVERTY

COALITION ON CHARGING REPORT

On Wednesday 4th June NCIL chaired the launch of the report 'Charging into Poverty?' at Portcullis House in the House of Commons. The report results from a project NCIL have managed for the Coalition on Charging (which NCIL chairs). You may have seen the survey which we had asked disabled people, older people, carers and local organisations to complete. The survey findings are announced in the report and include the following:

- **80% of the people who no longer use care services say charges played a part in the decision to end using services. A fifth (22%) of people currently using services suggested they would also stop if charges rise.**
- **29% of individuals do not feel their essential expenditure (related to impairment/health condition) is taken into account in financial assessments to pay charges.**
- **A third (34%) of individuals have no choice over the services they use.**
- **Nearly three quarters (72%) of individuals and 81% of organisations believe the Government should consider care service charges for support at home in adult care reform plans.**



The report recommends that charges are fully considered in England care reform plans and their impact better understood. It also suggests that a new compulsory agreement be established settling more realistic levels of disability related expenditure.

Roger Berry MP was the 'host' of the launch and it was well attended by Coalition members and politicians from the three main political parties. A copy of the report is available on our website www.ncil.org.uk or by e mailing infoassistant@ncil.org.uk

An individual response to the report

Dear Sirs

I have just found - quite by accident - the report: Charging into poverty and having read it I have to agree with every word.

My husband - Jim - has very severe Alzheimer's, is aged 84, and I have been caring for him at home for the last 5 years.

We have had help from an agency for the last 3 years, over 50 of them - from 4 companies, and in March this year we finally got a trust up and running to buy his care.

Our charges until the day the trust started were £4.09 per week, but the day after the trust started, Social Services sent someone to do a financial review. I was not given any advice on benefits, and was not told about the capital limits.

It was chaos and finished with me in tears and being told our charges would go up by £130 per week. I took fright and paid off our mortgage, and made a formal complaint, which was never acknowledged.

Eventually the review was done again, and after a massive fight the charges have been reduced to £66.41 per week, but are to rise to £86 in November, and £148 per week from January 2009.

I am now embroiled in part 2 of the complaints procedure, which in itself is a nightmare, but I have said if the charges are not changed I will close down the trust.

It seems to me the fairer charging policy is not in the least bit fair - as it is given with one hand and taken away with the other, and tries to reduce everyone to the lowest common denominator.

Now I get a state pension, that is deemed fair play and taken into account, although my carers allowance wasn't - but then I lost that when I got my pension anyway.

I thoroughly sympathise with all those people quoted, and it is obvious I am not alone, although it seems like it most of the time. Wouldn't it be wonderful if some of those people making the rules were to swap places with those like us, just for a few days. Just maybe they would then begin to understand.

Thank you for reading this,

Yours sincerely - Mrs Reid

On 11th June 2008 the third national action called by the Our Lives our Choices coalition took place. You may remember that on 18th June last year we held a national rally at the end of Downing Street followed by the official launch of the campaign for the Disabled Persons (Independent Living) Bill. Last October we held a very successful lobby of Parliament. This time we held a national rally followed by another lobby of Parliament.

The progress of the Bill is slow. It has now been introduced into the House of Lords three times. Where it gets stuck is in the House of Commons but, as with civil rights in the 1990s, we are not about to give up!



As well as campaigning for the Bill itself, we are also lobbying to get as many parts of the Bill as we can into other pieces of legislation to give them a chance of getting passed. We now have a really good opportunity to get that part of the IL Bill that is about being able to take your care package with you if you move from one local authority area to another passed. As a result of activity in the House of Lords an amendment will be put to the Health and Social Care bill by Baroness Jane Campbell later this month.

The Conservatives and Lib Democrats support this amendment as do many Labour and cross bench peers. If the Lords votes in favour of the amend-

ment, and there is every chance they will, then the Government may decide to try and overturn it when the Bill returns to the Commons. We need MPs of all parties to send a strong message that they will vote to keep the amendment in. So please tell your MP how important this amendment is.

Baroness Jane Campbell is intending to press for a provision in the Health and Social Care Bill that would ensure there is a disabled person on the board of the new Care Quality Commission. We need to back Jane up on this one too as it would help to put independent living at the heart of the health and social care regulator.

And there's more! There is an amendment down to the Housing Bill which would create a statutory duty on local authorities to compile registers of disability accessible properties. Tell your MP how important that is too.

So come on these opportunities don't come round very often, we have to make the most of them to get what we want – independent living. Nothing was ever changed by doing nothing and giving up. If you want further information contact **Sue Bott**, **Kevin Caulfield** or **Neil Coyle** at NCIL or policy@ncil.org.uk



NoLimits is the only national independent living exhibition to cover the entire disability sector. See www.nolimitsshow.co.uk

The show brings together the complete range of disability products and services allowing trade buyers, health professionals, carers AND disabled people to source new products and services to help improve their lives.

New Market – New Show

The show is a lifestyle event showcasing living aids, assistive technology, mobility aids, lifestyle, home and leisure products to inspire and improve lives.

Through compelling content and exciting activities the show will provide an informative and inspirational event creating a stimulating environment for both trade and consumer visitors to interact with and purchase from exhibitors.



UK CONSIDERING RESERVATIONS TO UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The fight for disabled people's human rights continues now. The Government plans to ratify the UN Convention on the Rights of Persons with Disabilities with reservations. Despite signing the UN Convention which would guarantee disabled people the same human rights which non disabled people take for granted, the Government wants to opt out of protecting some of those rights by placing reservations against some of the key Convention Articles and placing different interpretations on some of the words used in the Convention. This 'dolly mixture' approach to disabled people's human rights will not do and we need to take urgent action, right now.

The Government is considering a reservation against Article 19 (Living Independently and being included in the Community) that would prevent disabled people having a right to live where they want and with whom. Despite the Government's rhetoric about independent living, they still want to take away our rights to choose where we want to live and with who. Forcing disabled people into nursing, residential or group homes is at odds with the Department of Health's strategy on the roll out of individualised budgets and direct payments. Individual Budgets and Direct Payments underpin the DOH's Independent Living Strategy and are central to the policy aims in the 'Improving the Life Chances of Disabled People' report published in 2005.

The Government is also planning to reserve against Article 24 (Education) which means the Government is happy to continue to ignore our human right to access mainstream education, with all necessary support, within schools and colleges.



The Government clearly has no understanding about the life-long damage that segregated special schools have inflicted on disabled people. Where disabled people receive their education has a major impact on their self esteem, their sense of feeling part of the community and their life chances as they make the transition to adulthood. Evidence shows that disabled students leaving mainstream schools leave with higher self-esteem than their segregated special school counterparts. Opting out of protecting the right to inclusive education for disabled people does not square with Articles 3 and 8 requiring Government to raise awareness of positive perceptions of disabled people. Without the right to inclusive education, disabled and non



disabled students are going to miss out on mutual understanding which is the basis of a society that values difference and promotes equality.

We know that the Governments track record of eroding the rights of disabled people with mental health conditions so it will be no surprise that the Government plans to continue to dehumanise users and survivors of the mental health system by considering reservations against those Articles which would offer protections to those deemed to be without decision-making capacity or those deemed to be a ‘danger’ to themselves or others. With the Mental Health Act now in full swing, doctors have additional powers to section,

forcibly treated and lock up anyone whose behaviour which is perceived to be putting the public at danger. No wonder the Government is unwilling to comply with the protections included in the UN Convention.

It is important to remember that the same Articles also offer protections to disabled people with learning difficulties human rights, where their capacity is questioned by others. The recent “A Life like Any Other” human rights inquiry conducted by a Joint Committee on Human Rights, of MPs and Peers, concluded that the Government has simply not done enough to promote the human rights of disabled people with learning difficulties.

The Government has concerns about others aspects of the UN Convention including the right of disabled people to be able to come to the ►

- UK and live. The Government is also concerned that the UN Convention would allow disabled people to join the armed forces. Whilst we do not believe that there are vast numbers of disabled people desperate to join the armed forces, the Government appears to be placing conditions on a number of our fundamental rights and freedoms and that is why we believe that the Government cannot pick or choose which of our rights, as disabled people, it is willing to recognise.

Ratification must cover all aspects of the UN Convention and not just those Articles the Government thinks are possible to implement now. The UN Convention includes a 'progressive realisation of rights' – this means that Governments can, in some circumstances, take their time to implement different elements of treaty.

Disabled people are disappointed by the Government's apparent back tracking on its commitment to the full recognition of disabled Briton's human rights. This is particularly difficult to understand when we know that the UK took such a important and leading role in getting the UN Convention on the Rights of Persons with Disabilities agreed by UN Member states back in 2006.

We need to act now to make sure that the Government keeps to its promise to uphold all of disabled people's human rights by ensuring ratification without reservations by doing three simple and sweet things:

1. Contact you MP and get him or her to put pressure on Government to ratify the UN Disability Convention with no ifs and buts with the following areas - place of residence, inclusive education, armed forces employment and any further reservations or Government interpretations of other Articles which will restrict disabled people's human rights
2. Contact all the Constituency Political Parties Chairpersons
3. Sign the 10 Downing Street petition
<http://petitions.pm.gov.uk/noreservations/>

For further information contact Rachel Hurst at
Disability Awareness in Action
Telephone Number: 01666 837 671
Email Address: rachel.daa@btinternet.com
Website: www.daa.org.uk

Simone Aspis

(On behalf of the UN Convention Campaign Coalition) and
Brent Association of Disabled Peoples Member

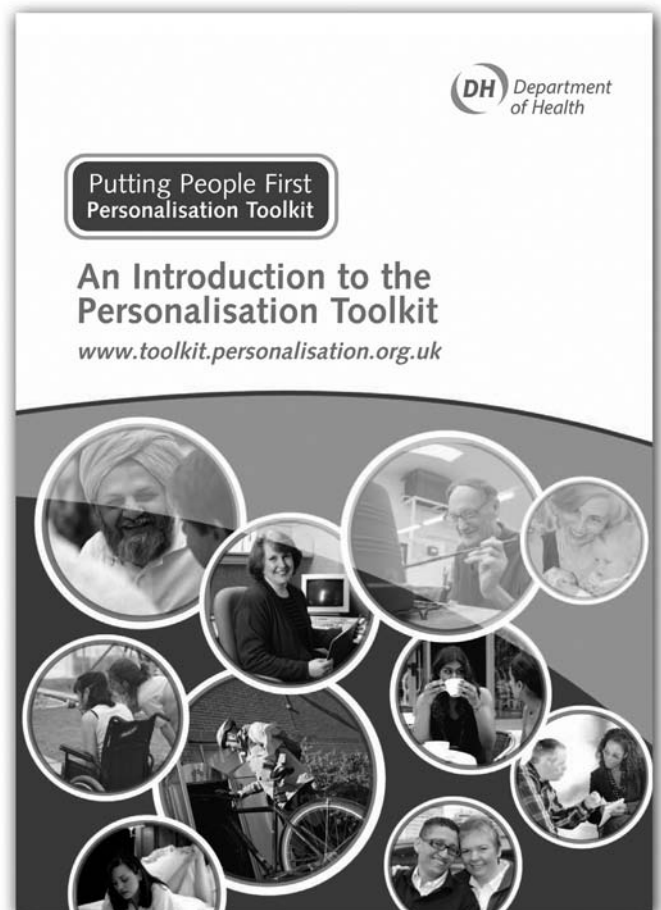
INDIVIDUAL BUDGETS

Personalisation Toolkit produced by Care Services Improvement Partnership (CSIP)

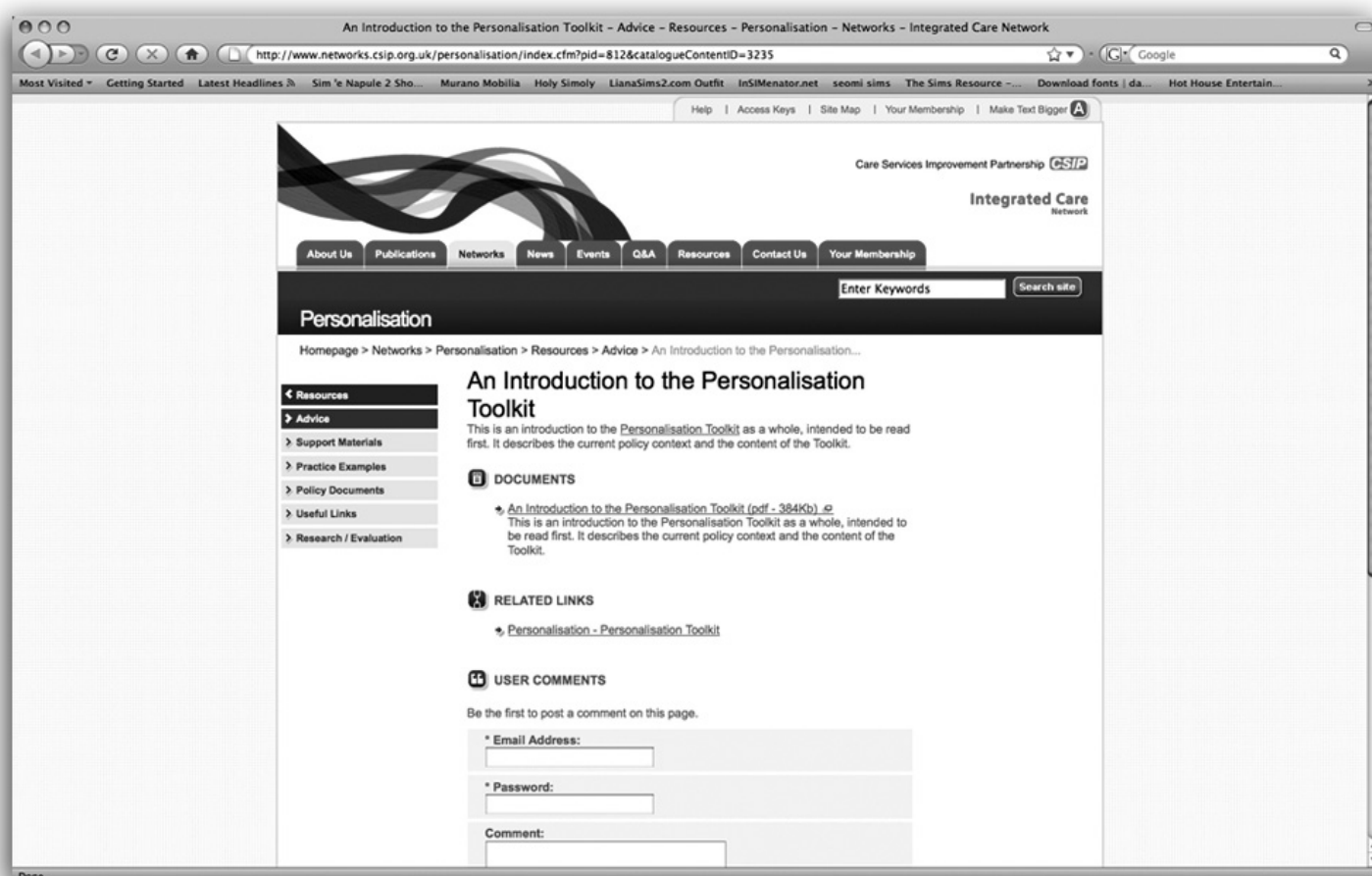
The Personalisation toolkit is an on-line resource to support councils to begin to plan and deliver the transformation of their social care systems, as set out in Putting People First. Its main focus is on learning from the Individual Budget Pilot programme. As councils plan their transformation programmes, it is important, of course, to use these materials alongside others which focus on the other key priorities, including early intervention, prevention and efficiency.

The toolkit contains a range of types of material:

- **Planning for Transformation framework** material provides the structure for the toolkit and has been produced to support councils to conceptualise, plan and communicate their transformation programme.
- It builds upon established programme planning best practice, tailored to the specific challenge of introducing a system of self-directed support. Councils can easily adapt this to a wider transformation programme laid out in Putting People First.
- In addition to recommendations of the necessary steps to be taken, the framework also provides a wealth of templates, risk registers and examples from councils. A financial modelling tool is available to help councils project future demands and understand levers for sustainability.
- **Tools and guides** that summarise learning so far about critical ►

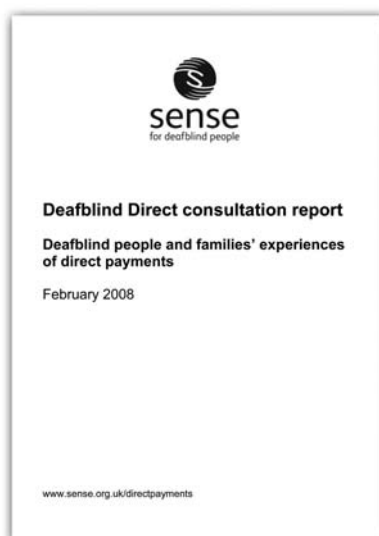


- ▶ issues and areas of development necessary to introduce a system of self-directed support, such as resource allocation, brokerage and support planning, equal access issues etc - these are mainly found within the Blueprint section.
- **Examples from individual budget pilot sites** of plans, policies and protocols developed to introduce a new system.



You can navigate the toolkit through programme planning stages, finding information and guides relevant to your particular stage of development. Given that detailed work to design your new systems happens at 'Blueprint stage' you can find specific guides and tools to develop different parts of your personal budget system in this section.

Apart from social care, the individual budget pilot programme tested the inclusion of a number of different funding streams in a person's budget: Integrated Community Equipment Services; Access To Work; the Independent Living Funds; Disabled Facilities Grant and Supporting People. Learning about these funding streams will be available following the publication of the national evaluation of the pilot programme.



For your information, Sense, the national deafblind charity, has published a report on its research into direct payments. From June to November 2007, Sense's Deafblind Direct project consulted deafblind people and families on their experiences of direct payments. Respondents included individuals who use direct payments and those who had thought about using them. The full report includes key findings, individuals' own experiences and recommendations for the Government, local authorities, CSCI, local support services and Sense.

Information about Deafblind Direct and both the report summary and full report can be found at

Simon Shaw, Deafblind Direct Coordinator, Sense
Email: simon.shaw@sense.org.uk
Voice and text: 020 7014 9386
www.sense.org.uk/directpayments

Books: Community Care and the Law

A must for CILs! Or your local library

Author: **Luke Clements and Pauline Thompson**

Community Care and the Law has become the leading text for lawyers, policy workers, local authorities and voluntary sector advisers and carers. Full Price: £48 Edition: Fourth (October 2007)

'This gem of a book ... sets out everything you could possibly want to know about community care law and practice (and much that you didn't know existed) ... I would urge you to buy this book.' *Mind*

'... an indispensable guide for those working in the field of community care.' *Adviser*

This is a key text for lawyers, advisers, local authorities and charities working in the field of community care. It provides essential information about social service functions and regulatory regimes.' *Child Right*

To purchase contact Legal Action Group Tel: 020 7833 2931
E-mail: lag@lag.org.uk

A second round of the User-led Organisations Development Fund is available for 2009/10 for user-led organisations to apply to deliver Action and Learning Sites up to March 2010.

These will develop ways of becoming an organisation that meets the Life Chances recommendation and then share learning with other organisations and groups across the country. This follows the successful application by 12 sites during the first round of funding during 2008-09.

The Action and Learning approach is driven by an emphasis on locally created solutions to common concerns and problems. For the purpose of applications to the User-led Organisations Development Fund, a user-led organisation is defined as: “one where the people the organisation represents, or provides a service to, have a majority on the Management Committee or Board and where there is clear accountability to members and/or service users.”

The User-led Organisation must be led and controlled by the people it works with. Applications made in partnership with another organisation are welcome, but must be led by the user-led organisation.

Closing date for receipt of applications from User-led Organisations: 5pm Monday 28 July 2008

User led Organizations Design Criteria

As a minimum user-led organisations should provide the following:

- Information and advice
- Advocacy and peer support
- Support in using individual budgets or other forms of self-directed support
- Support in recruiting and employing personal assistants
- Assistance with self-assessment
- Disability equality training

- Assistance with self-assessment
- Support implementation of the Disability Equality Duty by public sector organisations in the locality



15 User-led organisations should adhere to the following standards:

- Work from a social model of disability perspective
- Promotes independent living
- Promotes people's human and other legal rights
- Is shaped and driven by the initiative and demand of the organisation's constituency
- Is peer support based
- Covers all local disabled people, carers, and other people who use support either directly or by establishing links with other local organisations or networks
- Is non-discriminatory and recognises and works with diversity in terms of race, religion and belief, gender, sexual orientation, disability and age
- Recognises that carers have their own needs and requirements as carers
- Engages the organisation's constituents in decision making processes at every level of their organisation

► **User-led organisations should have the following characteristics:**

- Provide support to enable people to exercise choice and control
- Is a legally constituted organisation
- Has a minimum of 75% of the voting members on the management board drawn from the organisation's constituency
- Is able to demonstrate that the organisation's constituents are effectively supported to play a full and active role in decision making
- Has a clear management structure
- Has robust and rigorous systems for running a sustainable organisation such as financial management/contingency planning
- Is financially sustainable as there will be no ongoing central government funding
- Has paid employees some of whom must be disabled people
- Identifies the diverse needs of the local population and contributes to meeting those needs
- Is accountable to the organisation's constituents and represents their views at a local level
- Supports the participation of the constituents in designing, delivering and monitoring the organisation's service
- Works with commissioners to improve commissioning and procurement

Agreed by DH ULO Project Board May 2007

NCIL Futurebuilders Grant

NCIL is now working intensively with 6 organisations who applied to work with us to develop business plans for future funding bids in 2009/ 10.

These organisations are Cheshire Centre for Independent Living, DASL, Disability Wessex, Lancashire Centre for Independent Living, South Yorkshire CIL, West of England CIL,

We have a wider development group that includes Derbyshire CIL, Disability Croydon, ILA West Sussex and Sutton CIL.

This project will run until March 2009

RESEARCH PROJECT FOR THE EQUALITY AND HUMAN RIGHTS COMMISSION:

The impact of selected human rights cases on public service provision

The Equality and Human Rights Commission has asked us to find out about the impact of the Human Rights Act. We are doing this work as part of their Inquiry which will try to promote awareness, understanding and protection of human rights.

Our project will look at some important legal cases that have been taken to court using the Human Rights Act. We will talk to people who provide public



services, like social care; about whether these cases have changed the way they do their job. We also want to know if the cases have made a difference to the lives of disabled people.

Two of the most important cases are:

R v East Sussex County Council - the family of two adult sisters who were disabled didn't agree with a council's rules. The council said that care workers always had to use a hoist if they needed to lift the two women. That meant that the sisters could not go riding, or shopping, and that sometimes they did not get the help they needed. When the case went to court, the judge disagreed with the council. The Human Rights Act meant that the council had to balance the dignity of the two sisters against the health and safety of its care staff. The court said it was against the law to have a policy that said "no manual lifting". They said that any risk assessment should be based on the individual circumstances of the person concerned, and their needs. So that meant that sometimes the two sisters would need care workers to lift them without using equipment. ►

- ***Bernard v Enfield*** - a woman who is a wheelchair user and who is incontinent and has diabetes was placed in a house which was not adapted to meet her needs. This meant she had to live in one room and could not get to the toilet. She also could not help care for her children, leaving her husband to care for them all.

Even though the council knew this, it left the family in the house for 20 months. The court said that the local authority had an obligation to enable the disabled woman to live in dignity and to enjoy as normal a family life as possible. The court also said that users of public services who need particular assistance should not have to wait an unduly long time to get the services they need.

Why we are contacting NCIL members?

We would like to invite NCIL members to contribute to this project by providing information or personal experience on any of the following questions:

East Sussex:

- in your experience, are there still policies in place which say that carers cannot lift disabled people manually - that is, without using equipment?
- where such a policy is in place, does it prevent disabled people from doing the things they want to do, like going out or doing a particular activity?
- In your experience, has this Human Rights Act case had any impact on the ability of people who sometimes need to be lifted manually to get access to the services and support they need? If so, what kind of impact has there been?
- are you aware of any examples where the principles established in this case have been used to help negotiate a better outcome for a person with manual handling needs?

Bernard v Enfield:

- in your experience, is the placing of disabled people in unsuitable accommodation that hasn't been adapted to meet their needs a significant or widespread problem?
- do you think this Human Rights Act case has had any impact on how

local authorities make decisions about allocating housing to disabled people? If so, what kind of impact has there been?

- are you aware of any examples where the principles established in this case have been used to negotiate a better outcome for a disabled person?

Please note that, unfortunately, we do not have the capacity to follow up or investigate individual stories. Please also be assured that we will treat any responses in the strictest confidence. When we write up our final report, we will not use any information you give us without your permission.

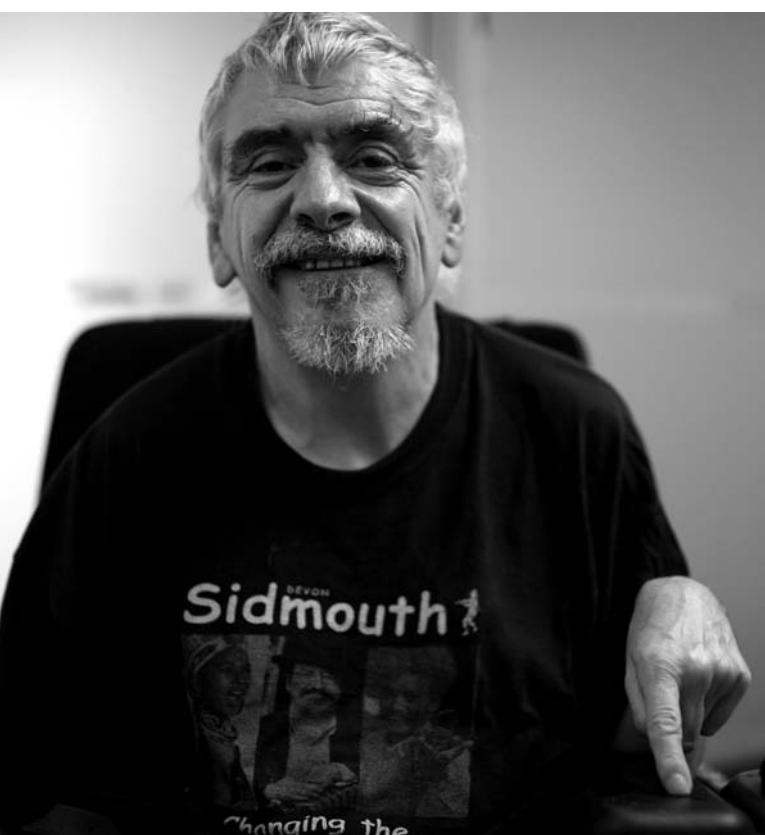
Who is conducting the research?

We are a small team drawn from London Metropolitan University's Human Rights and Social Justice Research Institute and the consultancy Global Partners and Associates.

How to contact us

If you would like to share your experience with us, please respond by **Friday 25th 2008**. Please contact Alice Donald at alice@alicedonald.co.uk. Thank you very much!

SAD NEWS



Alan Desborough

Many of you will know of Des who attended most of the Our Lives Our Choices meetings. Sadly Des died of cancer on 11th April. He was a great campaigner for disability rights. Having found his own way out of institutional living he was determined that every other disabled person should be able to have independent living. He was NCIL's independent living campaign worker for two years. ►

- He was also a local activist playing a key role in Disability Action in Islington. Des's commitment and humour will be greatly missed.

Disability world mourns loss of activist

The disability world is mourning one of its most popular activists, Sue Maynard Campbell MBE (pictured), who died in the early hours of yesterday morning (21 May). Ms Maynard Campbell was one of the founders of the British Council of Disabled People and a leading figure and former chair of the Association of Disabled Professionals.



A qualified solicitor, she was chair of the Group for Solicitors with Disabilities and managing director of the disability consultancy Equal Ability CIC. She also set up the Ceiling Hoist users Club and worked to encourage hotels to install hoists in their rooms. And she was a former chair of the Advisory Committee for Disabled People in Employment and Training.

Over the years, she wrote and campaigned on issues such as barriers to independent living, right to life issues and the use of “do not resuscitate” notices in hospitals, having been the victim herself of such a notice during a hospital stay in 1998.

In 2002, Ms Maynard Campbell was awarded an MBE.

Douglas Campbell (no relation), chair of Mobilise, who knew her well and worked with her on many occasions, said she was a “constant campaigner”. He said: “She wouldn’t accept half measures. She expected people to properly meet the needs of disabled people. She also took on causes that were not nationally popular, such as ceiling hoists.”

As a person, he said, she was “great fun and full of life”. “It is a great loss for the disability world and, as far as I am concerned, the loss of a good friend.”

In a statement on its website, the Ceiling Hoist users Club said: “She will be missed by her family, friends and colleagues and will be remembered for her achievements and sheer determination. Sue was an inspiration to us all.”

HIGH COURT RULES THAT

ANTI-DISCRIMINATION LAW DOES APPLY



In 2006, Peter Gichura was detained twice in Harmondsworth in appalling conditions, including: not being able to use the bathroom and toilet properly and inadequate medical treatment, given the wrong medication.

Under the 1995 Disability Discrimination Act (DDA), which outlaws discrimination in employment, and provision of goods and services, Mr Gichura sued the Home Office (HO) and Kalyx Ltd, the private company which runs Harmondsworth detention centre, for compensation for discriminatory treatment. The HO & Kalyx tried to get the case dropped, claiming that detention for immigration control is exempt from anti-discrimination law.

On 20 May, the High Court ruled that the DDA applies to the services (food, washing facilities, etc.) which a person receives once s/he has been detained. Therefore Mr Gichura's case should go forward to trial. *This ruling establishes that all disabled prisoners in custody, including those in prison, before December 2006 (when new regulations came in) do have the protection of anti-discrimination legislation.*

In May 2007, the Home Office tried to send Mr Gichura back to Kenya, but were stopped when a judge ruled they could not deport their opponent in a precedent-setting case.

Campaigning with *Payday* and *WinVisible*, based at the Crossroads Women's Centre, Mr Gichura has received widespread public sympathy. Anne Owers, HM Chief Inspector of Prisons, condemned the conditions at Harmondsworth as "the poorest report we have issued on an Immigration Removal Centre" (Nov 2006). Conditions at Harmondsworth have also prompted ongoing protests, including hunger strikes, by those being held there.

For details contact: **WinVisible** (women with visible and invisible disabilities) Tel 020 7482 2496 (voice/minicom) winvisible@allwomenscount.net
www.allwomenscount.net/EWC%20WwDiss/WVindex.htm



**National Centre for
Independent Living**



Have your launch, training event, meeting in Central London.

TO BOOK CONTACT:

**NATIONAL CENTRE FOR
INDEPENDENT LIVING (NCIL)**

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EMAIL: office@ncil.org.uk

WEB: www.ncil.org.uk





**National Centre for
Independent Living**



HIRE RATES

MONDAY – FRIDAY 9.30AM –5.30PM

	HOURLY RATE	FULL DAY*	HALF DAY*
NCIL MEMBERS	£40 PER HOUR	£305	£175
NON-MEMBERS	£50 PER HOUR	£380	£220

ROOM FEATURES

54.4 SQ METRE

BOARDROOM

THEATRE

THEATRE WITH
WHEELCHAIR USERS

ACCESSIBLE BUILDING

CAPACITY

20

45

35

*FULL-DAY: 09.30AM-5.30PM
HALF DAY: 09.30-1.30PM /1.30PM-5.30PM



SUPPORT



You can get involved and support NCIL by:

Making a donation

Sponsoring one of our activities

Taking part in one of our campaigns

Contributing to our newsletter

Joining as a member

Using our training services

Contact us

General information: info@ncil.org.uk

Campaigning: policy@ncil.org.uk

Training and consultancy: projects@ncil.org.uk

Administration: office@ncil.org.uk

Finance: finance@ncil.org.uk

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